

National Birth Defects Prevention Study Study Participation Rates Standard Definitions

Calculation of participation rates is needed to monitor and evaluate the study progress and interpret study outcome. The targeted participation rate is 75% for both cases and controls. So that rates are comparable across sites, it is important for participation rates to be calculated at each CBDRP using the same methods. Eligibility and participation rates will be calculated using the following definitions agreed upon by all CBDRP.

1. Eligibility Rates

A. Eligibility Rate for Cases:

Numerator = All eligible cases determined by the following criteria: appropriate diagnostic code; if stillborn > 20 weeks gestational age or >500 grams; maternal residence at birth in defined geographic area; diagnosis within 12 months of birth; birth mother living; not in foster care or adopted; mother is Spanish or English speaking; other exclusions [there are no special circumstances for excluding this case (e.g., Center employee, physician refusal, etc)].

Denominator = All eligible cases determined by the following criteria: appropriate diagnostic code; if stillborn > 20 weeks gestational age or >500 grams; maternal residence at birth in defined geographic area.

B. Eligibility Rate for Controls:

Numerator = All eligible controls determined by the following criteria: live birth; has no major birth defect; maternal residence at birth in defined geographic area; birth mother living; not in foster care or adopted; mother is Spanish or English speaking; other exclusions [there are no special circumstances for excluding this control (e.g., Center employee, physician refusal, etc)].

Denominator = All eligible controls determined by the following criteria: live birth; has no major birth defect; maternal residence at birth in defined geographic area.

C. Exclusion Information for Eligibility Rates

Cases and controls that are in the denominator but not in the numerator should be counted by the following categories as to why they are being excluded:

- mother not living
- child in foster care or adopted
- mother does not speak English or Spanish
- mother has mental or physical health problem
- mother is incarcerated
- physician refusal
- Other exclusions (specify)

2. Participation Rates

A. Participation Rate for Cases:

Numerator = case interviews completed.

Denominator = All cases from numerator of eligibility rate.

B. Participation Rate for Controls:

Numerator = control interviews completed.

Denominator = All controls from numerator of eligibility rate.

C. Exclusion Information

Cases and controls that are in the denominator but not in the numerator should be counted by the following categories indicating why the interview was not completed:

- mother could not be located
- mother refused
- 15 month interview deadline expired
- interview started but not completed
- other exclusion (specify)